



Simplifying health care transitions for those with disabilities

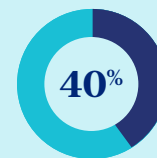
Helping ensure better care, quality and outcomes throughout every life phase

People with disabilities can face several barriers to accessing comprehensive primary care, as outlined in the issue brief [Improving Primary Care for People with Disabilities](#) co-authored by UnitedHealthcare Community & State's independent [National Federally Qualified Health Center \(FQHC\) Advisory Board](#) and [National Advisory Board](#). The Boards recognized that an important aspect of delivering comprehensive primary care includes intentional care coordination during times of life transition. The following brief explores common health care challenges people with disabilities face as they age, as well as potential policies that could mitigate those obstacles.

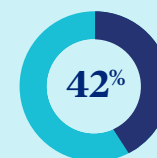
Life transitions naturally lead to health care transitions as people age. However, individuals with disabilities face additional challenges as they make these transitions. Some of the challenges they face include:

- A higher risk for a decline in health after transitioning from pediatric to adult health care.
- Simultaneous transition challenges related to education (including the loss of school-based services), employment and community organizations, compounding the stress of changing providers.
- Limited support when switching from a pediatric to an adult provider.⁴
- Interruptions in care linked to poor health care transitions.
- More than twice the risk of living in poverty as the general population⁵ – and even more so for Black, Indigenous, and People of Color (BIPOC) – which can make transitions more difficult.
- A greater risk of experiencing trauma and abuse that affects mental, physical, social, emotional and/or spiritual well-being⁶ – which requires providers to understand trauma-informed care.
- For indigenous people with disabilities living in sovereign communities, a greater risk of discrimination because laws such as the Americans with Disabilities Act do not apply.

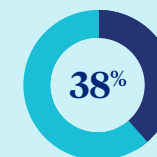
BIPOC with disabilities are:



more likely to be unemployed¹



more likely to be in poverty²



more likely to report fair or poor health³

as compared to their White peers.

Approaches to Transition

Health care transition programs are important for the general population, but they're critical for those with a disability. The relationships that individuals with disabilities build with health care providers can feel very significant to the individual because they have regular engagement. This is especially true for primary care providers who serve individuals' needs across their lifespan. This can make transitioning from one care provider to another more difficult. It's not just about ending the relationship with a trusted provider, it's also about the stress of finding a new provider who understands their complex health care needs and with whom they believe they will be able to build a similar relationship.

Structured health care transition processes are directly correlated to positive health outcomes, according to a systematic review by The National Alliance to Advance Adolescent Health.⁷ Yet individuals with a disability make more health care transitions on average than those without a disability. There are many forms of disability, including physical, sensory, developmental, intellectual, and the higher the level of need, the more likely it is the individual will encounter barriers in the process of transitioning care during a life transition.⁸

Managed care organizations (MCOs), providers and policymakers can benefit from making primary care transition success a priority to enhance quality of life for individuals with a disability and can improve the overall health outcomes for this population. In particular, primary care providers who have long-standing relationships with those who have disabilities are uniquely positioned to provide person-centered care during the many life transitions they experience.

Examples of Common Health Care Transitions by Life Phase

Birth



Early childhood: From infancy to early physical, cognitive, language and social-emotional development.

Adolescence



Age 5-6: From home-based learning to school.
Age 14-16: Individualized education program statement of transition required. From non-work to job training and employment.
Childbearing age: Learn about puberty, sexual and reproductive health.
General: From one school to another as education progresses.

Adult



Age 18: From child to legal adult able to make treatment decisions. From non-voter to voter.
Age 19: From CHIP coverage to own plan (for some).
Age 21: From parental Medicaid coverage to own plan for FT students.
Age 26: From parental private insurance to own insurance, or from Medicaid to own insurance for some former foster youth.
General: From home care to independent living/ group home. From high school to college. From student to graduate.

Older Years



Age 65: Medicare qualified and sometimes Medicaid (for dual eligibles).
General: From independent living to assisted living.

End of Life



General: End-of-life planning, entering hospice.

How is a health care transition different for those living with a disability?

Individuals with disabilities tend to experience more health care transitions during their lifetime than those without a disability. Additional challenges can arise for those who belong to both the disability and BIPOC communities, and also for foster youth with disabilities. Cultural difference sometimes compound communication difficulties that can occur for individuals with disabilities. These differences represent opportunities for all who support this population to apply person-centered care principles at the many transitions throughout an individual's life. They've built the relationship, they understand the individual's needs, and they are in a position to not only ensure those needs are met, but also help the individual make informed care decisions along the way.



Pediatric to adult provider transition. With this change, the main contact with the provider may largely shift from a caregiver or parent to the individual. This can create a stressful event for the individual and the caregiver, who may have been an integral part of health decisions over the preceding several years. Upon turning 18, individuals have the legal right to make their own treatment decisions. While this empowers individuals with a disability to take charge of their health, they sometimes need provider support in making their health care choices even as adults.¹¹ For those individuals still needing their caregivers or parents to engage with providers and health plans on their behalf, documentation (e.g., Medical Power of Attorney) is necessary.



Life stage transitions: As people with disabilities move from childhood, to adolescence, to child-bearing age, they need information relating to puberty, sexual and reproductive health – just like those without disabilities. However, because people with disabilities face triple the risk of physical and sexual abuse, plain-language discussions with a provider can lead to better understanding, awareness, self-advocacy and safety.¹²



Insurance coverage transition. While most youth with special health care needs have insurance coverage, the transition from youth to adult will include one or more insurance transitions, depending on age and the type of coverage originally in place and state of residence. It's important to develop an insurance transition plan and discuss it before milestones occur. Helping the individual understand the change and positioning it as a positive step in their self-advocacy journey can lessen anxiety.¹³ The following are examples of different insurance coverage transitions:

- **Age 18:** Patients are considered legally independent, although many with a disability may still need support to make health care decisions at this age. For most states, Medicaid coverage ends unless the patient is enrolled in the foster care system or can re-qualify for coverage as an adult. For other states, Medicaid may be extended until age 21 for those who are full-time students.
- **Age 19:** Coverage through the Children's Health Insurance Program (CHIP) ends.
- **Age 26:** Coverage through Medicaid for former foster youth ends, and coverage for those enrolled under a parents' private insurance ends.

Disability by the numbers across all self-direction opportunities:

13.2%

of U.S. population has a disability⁹

<25%

of publicly insured special needs youth receive health care transition preparation¹⁰



Setting transition. Other life changes that lead to health care transitions include moving from one's family home to own home/apartment, or from an independent living arrangement to a group home or to assisted living. To maintain the best possible outcomes for individuals with a disability throughout every phase of life, it's important to develop primary care transition processes.

How can barriers to successful health care transition be removed?

Transition improvements for individuals with a disability have great potential to remove barriers to care, impact care quality and improve health outcomes.

Findings show that while every disease-specific population encounters transition barriers, the commonalities for all, including individuals with a disability, were:

- Not wanting to shift from a provider with whom they've built a longstanding relationship
- Difficulty in finding a new provider
- Limited access to a new provider who understands their needs and accepts their insurance
- Lacking needed skills to manage their own care

Providers play a key role in helping individuals overcome these barriers through transition process design. This includes care coordination among all stakeholders, from MCOs to caregivers in providing services that range from home- and community-based services to behavioral health. **A focus on whole-person care is key to ensuring the transition contributes to their overall quality of life.**

Full-scope transition planning during major transitions such as establishing a relationship with a new primary care provider and transitioning to long-term services and supports or home- and community-based services can include:



Pre-appointment: Providers can start to build a relationship with a referral who has a disability even before the first appointment. Here are a few things to consider before the appointment:

- Ask if any enabling services will be needed to support the visit, including interpreter services or transportation.
- Ensure the facility and all necessary materials (e.g., websites, paperwork) meet ADA standards.
- Confirm if they are planning to or would like to have someone attend the visit to take notes.
- Confirm level of guardianship or decision making granted to a family member or caregiver.
- Consider having an introductory visit via telehealth prior to the in-person visit.
- Show an understanding of both their health conditions and their individual needs.
- Create a bridge between the former provider and the new one.
- Provide a brief description of what to expect at the initial visit and a reminder.

Key Transition Elements¹⁴

The National Transitions of Care Coalition's ([NTOCC](#)) seven key elements of care transition:

- Medication management
- Transition planning
- Patient and family engagement
- Information transfer
- Follow-up care
- Health care provider engagement
- Shared accountability across providers and organizations



During initial visit: Provide a warm welcome, reassuring them of provider expertise areas and specific understanding of individual needs. Due to the increased incidence of trauma and higher risk of abuse among those with disabilities, having a trauma-informed care mindset is helpful in preparing for the initial visit. If necessary:

- Ensure the examination room is quiet and accommodating for sensitive individuals.
- Review health history to help them feel understood and seen.
- If possible, highlight what will be different and similar as compared to the previous provider.



Post-visit: Follow-up communications are key to relationship building.

- Confirm details discussed during the visit in writing, particularly any care instructions or recommendations.
- Thank them for trusting you with their health.
- Let them know you look forward to seeing them at the next visit.



On-going care coordination: Coordinating care among all types of providers, including home- and community-based care, long-term services and supports, transportation, and even personal caregivers can increase quality of life dramatically for individuals with a disability.

- Develop communication plan for all care touch points and care providers.
- Communicate with the individual to understand full scope of quality of life, including care experience with providers.

Transition in the future: Practice and policy opportunities

Improving health care transition outcomes — especially for those populations with disabilities — has the potential to increase consumer confidence in the health care system, according to the NTOCC. There is still room to improve communication, electronic health record standardization, care coordination, incentive-based payment systems, and performance measures. These changes are essential to ensure caregivers and families have the support they need to be able to interact with providers regarding the complex health care requirements that arise for people with disabilities.¹⁵

A team effort: Enabling healthy transition

From infancy to end of life, there are many opportunities to provide support to people who are living with a disability through health care transitions. Collaboration and strong communication between the individual and their caregivers, providers and Medicaid MCOs can help them achieve their full potential for independence, self-advocacy, and health.

To support these efforts, the Boards identified the following policy opportunities.



Continuity of Coverage: Medicaid eligibility is complicated. To support people with disabilities secure and maintain access to needed care over the course of their life, states should:

- Consider implementing presumptive eligibility for Medicaid across all populations and include access to all services for which a person qualifies when using the presumptive eligibility pathway.
- Adopt 12-months continuous eligibility for children (via state plan amendment) and adults (via 1115 Authority).
- Implement passive enrollment for former foster youth, contingent on meeting Medicaid eligibility requirements.



Timely Access to Comprehensive Services: States should take action to provide individuals with disabilities access to services that meet their care needs as health and life circumstances change, including:

- Allow and support MCOs in equipping and strengthening provider networks to better meet the health and social needs of individuals with disabilities, including promoting trauma informed care.
- Increase access to skilled caregivers by creating opportunities for family members to be paid caregivers.
- Cover an array of services to meet a wide range of needs, regardless of diagnostic category, including enabling services (e.g., translation and transportation) that facilitate access to care.



Care Integration and Coordination: Positive health outcomes are more likely to be achieved when care is integrated and coordinated across all providers, particularly for people with disabilities who may require a broader array of services across multiple settings throughout their life. States should create an environment where MCOs and providers are encouraged to collaborate and communicate, including taking steps to:

- Support MCOs in developing and implementing incentive arrangements with primary care providers that focus on integrating care and coordinating services across multiple providers to facilitate access to person-centered care. Support the development of and incentivize participation in statewide data sharing platforms, including health information exchanges, that could facilitate health and social determinants of health (SDOH) related data sharing between providers.
- Allow health plan care coordinators to actively participate in school-related meetings with children, youth, and their families/caregivers and participate in the Individualized Education Program/504 plan development to help coordinate care with the member's primary care provider and avoid duplication of services.
- Allow adults with disabilities and their families/caregivers, including health plan coordinators and primary care providers to participate in meetings and in the development of their Individual Service Plan when receiving services through a local Developmental Disability Services agency.
- Support alternative payment models that offer primary care providers like FQHCs and other care providers additional flexibility to best meet the care needs of individuals with disabilities.

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Got Transition is a registered trademark of The National Alliance to Advance Adolescent Health.

Six Core Elements is a trademark of The National Alliance to Advance Adolescent Health.

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